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The objective of this study is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. Participants are paired with a trained breast cancer survivor who provides them with ongoing peer support, in addition to specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers receive the standard Reach to Recovery training, in addition to a two-day skills training which prepares them to become breast cancer peer support volunteers and advocates.

The third year of this four-year project has been devoted to continued implementation of the peer support program in five medical centers. Activities have included: (1) recruiting, interviewing and training volunteers; (2) providing support to volunteers; (3) recruiting participants; (4) matching volunteers with study participants; (5) obtaining follow-up data from participants at 3-months and 12-months; and (6) developing the code book for data entry and the plan for data analysis.

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Carl P. Sch 7/28/97

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Introduction

This report summarizes activities for the third year of a four-year study. The objective of this study is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. This randomized controlled trial asks four research questions:

1. Does this expanded program improve (a) quality of life with breast cancer; (b) participation with treatment decisions; and (c) satisfaction with care?
2. How do patient sociodemographic characteristics influence these outcomes?
3. What are the main benefits of this program?
4. Does participation in treatment decisions improve quality of life?

Women recruited into the study in five Kaiser Permanente medical centers are randomly assigned to the intervention or control group. Participants in the intervention group are paired with a trained breast cancer survivor (peer support volunteer or "peer supporter") who provides them, beginning at diagnosis, with ongoing peer support along with specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Participants in the control group receive the usual support services offered to women newly diagnosed with breast cancer, which in most cases includes a referral to Reach to Recovery.

Study volunteers received the standard Reach to Recovery training, in addition to a two-day skills training, which increased their problëmsolving, decision making and advocacy skills and prepared them to become breast cancer peer support volunteers. These trainings were not simply didactic presentations; they afforded participants the opportunity to learn new skills through exploring their own personal experience of diagnosis, treatment and follow-up of breast cancer, in order to identify any unresolved experiences that might impede a relationship with a newly diagnosed patient.

Body: Year Three Activities

The third year has been devoted to continued implementation of the peer support program in five medical centers. Facility-specific recruitment, volunteer training and support, and overall project maintenance have continued to comprise the heart of our work during the third year.

Activities have included: (1) recruiting, interviewing and training volunteers; (2) providing support to volunteers; (3) recruiting participants; (4) matching volunteers with study participants; (5) obtaining follow-up data from participants at 3-months and 12-months; and (6) developing the code book for data entry and the plan for data analysis.

Recruitment and training of volunteers was an essential component of Year Three, as it was of Year Two. We sought volunteers who, as closely as possible, matched the sociodemographics of

the women newly diagnosed at each facility. We worked with physicians and other health care providers at each of the study sites to furnish us with names of women living with breast cancer whom they thought would make good volunteers. Interested women were screened, both before and after the training, to assess their expectations of the peer support role and any concerns about fulfilling it they might have. In addition they were asked to make a one-year commitment to be involved in the project. While we accepted all women who were screened, one woman dropped out during the training, when she realized that she was not right for the program. We held four 3-day volunteer trainings this year, training 27 new volunteers. Over the course of the project, we held 10 trainings in total and trained 71 volunteers, 52 of whom were still active as of June 30, 1997. Twelve volunteers did not renew their commitment after the first year, 5 dropped out because their breast cancer recurred, and 2 women died.

As discussed in our Year One Annual Report, we decided during the first year of the project that volunteer recruitment and training could most effectively be conducted on an incremental basis. That way we could recruit new volunteers, as needed, who best matched (in terms of age, race/ethnicity, and marital status) the women who were being recruited into the study. Also, since we did not know, at the outset, how many "buddies" (newly diagnosed women with breast cancer) a "peer supporter" (peer support volunteer) could optimally work with at any one time we did not know until the project was underway how many peer supporters we would ultimately need. We found that this number varied according to several factors including the characteristics of the peer supporters (such as time availability, temperament, and experience) and the particular needs for education and support of the newly diagnosed women. The latter itself fluctuated at different points during the first year following the buddy's diagnosis. In general the level of involvement required of the volunteer diminished somewhat as her buddy moved further from diagnosis, freeing the volunteer to take on an additional buddy if the "match" was right. Thus, some volunteers were able to work with two or three buddies simultaneously while others only one.

We continued to supervise and support the volunteers during the third year, both in the monthly meetings and individually, as described in our Annual Report for Year Two. The process of going through the training and performing role of the peer supporter, of necessity, affords the volunteer frequent opportunities to confront any personal issues she may have regarding breast cancer. The role of staff (who were licensed clinical social workers or Registered Nurses) was to facilitate the review of these issues to promote healing. Their clinical skills were exceptionally valuable, especially when a peer support volunteer recurred or died. The following are some examples of other types of issues dealt with by staff. A common concern voiced by the peer supporters was a reluctance to be too "pushy" if a buddy said she "didn't need anything." In this situation, we talked about numerous ways one can offer support without being intrusive and also about how to tell when it is time for the volunteer to back off. Another volunteer concern was what to do if she had not undergone the *exact* treatment as her buddy. In order to maximize the resources of the volunteer pool, we would handle this concern in one of two ways. Either we would talk with the volunteer until she felt comfortable directing her buddy to the information or resource she needed or, if preferable, we would ask another volunteer who *did* have the missing experience to work with the buddy on a short-term basis.

Participant recruitment has continued to be a stimulating challenge. As described in last year's Annual Report, it has required developing and perfecting effective recruitment procedures at the five research sites--each of which has its own personality, culture, and attitudes about care delivery. Throughout the third year, project staff at each of the sites continued to identify eligible patients; obtain physician permission to contact their eligible patients; send out invitation packets (which included a baseline questionnaire and consent form); and make one follow-up telephone seven days after the letter was mailed to answer any questions and/or to send another invitation packet if needed.

Since beginning patient recruitment in October 1995 through the end of recruitment in June 1996, we recruited 291 patients into the study. As anticipated in our last Annual Report, this number is below our original estimate of 500 participants. Nevertheless our project biostatistician has concluded that our reduced numbers will not produce a dramatic change in the minimum detectable difference for our outcome measures. Our original sample size of 250 in each study group was estimated to provide sufficient power (80%) to detect a .25 standard deviation unit difference in the mean of each measure of effectiveness, using a two-sided Z-test and significance level = .05. A reduced sample size of 145 in each study group will provide sufficient power to detect a .33 standard deviation unit difference in the mean of each measure of effectiveness. This represents a 32% increase in the minimum detectable difference.

To date, our return rate for the three-month and the twelve-month questionnaires has been excellent. At this point in the follow-up period we have received a 92% return rate for the three-month questionnaires (216 questionnaires returned out of 235 questionnaires sent out) and also a 92% return rate for the twelve-month questionnaires (56 questionnaires returned out of 61 questionnaires sent out). We anticipate maintaining the same level of follow-up for the entire sample.

We extended the period of recruitment to the latest possible date (an additional six months from Month 30 to Month 36) in order to maximize the number of subjects available for analysis. We are confident that we will be able to make up this time during Year Four by editing and entering the data sooner than originally planned and by beginning the analysis before all the data is collected. We prepared for this eventuality during the current year by developing the code book for data entry and the plan for analysis. We will begin editing and entering the data from the baseline questionnaires immediately. We will enter all the data for the three-month questionnaires by Month 40. We will enter the data for the twelve-month questionnaires in batches: about half will be entered by Month 40, and three-quarters by Month 45. We will thus be able to begin the analysis by Month 40, as originally planned, and add in the data from the remaining twelve-month questionnaires as they are ready. Therefore, we anticipate being able to complete the statement of work on time, or in the least favorable eventuality, with a no cost extension of several months.

Conclusions

Year Three has been spent implementing the peer support intervention (including recruiting, training and supporting volunteers) and recruiting and obtaining follow-up data from

participants. In Year Four we will continue to support the volunteers, monitor participant follow-up, edit and enter the data, conduct the analysis and prepare the final report. In addition we plan to evaluate the impact of participating in the peer support program on the peer supporters and prepare a Leader's Guide which will assist the continued implementation the program in the facilities after the completion of the study. If the intervention proves effective we will work with the American Cancer Society, Kaiser Permanente, and other health care organizations in the community to develop ways to offer the program on an ongoing basis.